



**BIMTEK**

# **PELAYANAN PERAWATAN PALIATIF DAN PERAWATAN AKHIR KEHIDUPAN**

***dr. Ika Syamsul Huda MZ, SpPD, MPH***

***Ketua Tim Perawatan Paliatif  
RSUP dr. Kariadi Semarang***

[https://khn.org/wp-content/uploads/sites/2/2017/02/end-of-life0217\\_770.jpg?w=770](https://khn.org/wp-content/uploads/sites/2/2017/02/end-of-life0217_770.jpg?w=770)



# CURRICULUM VITAE

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**Anggota Perhimpunan Dokter Paliatif Indonesia (PERDOPIN)**  
**Anggota Masyarakat Paliatif Indonesia (MPI)**

A hand holding a butterfly against a sunset background with text overlay.

# PALLIATIVE CARE

## End-of-life care

[https://live.staticflickr.com/3776/10412968824\\_c1ee1d5348\\_b.jpg](https://live.staticflickr.com/3776/10412968824_c1ee1d5348_b.jpg)



# Mapping levels of palliative care development in 198 countries: the situation in 2017



## INDONESIA: **Isolated Palliative Care Provision**

*A country in this category is characterized by the development of palliative care activism that is still **patchy** in scope and **not well-supported**; sources of funding that are often heavily **donor-dependent**; limited availability of **morphine**; and **a small number** of palliative care services that are limited in relation to the size of the population.*

Prof. David Clark, dkk 2019

# MYTHS ABOUT PALLIATIVE CARE

MYTH 7: Palliative care is only provided in a hospital.



**FACT:** In many cases palliative care can be provided wherever the patient lives – home, long-term care facility, hospice or hospital. Sometimes the needs of the patient exceed what can be provided at home despite best efforts.

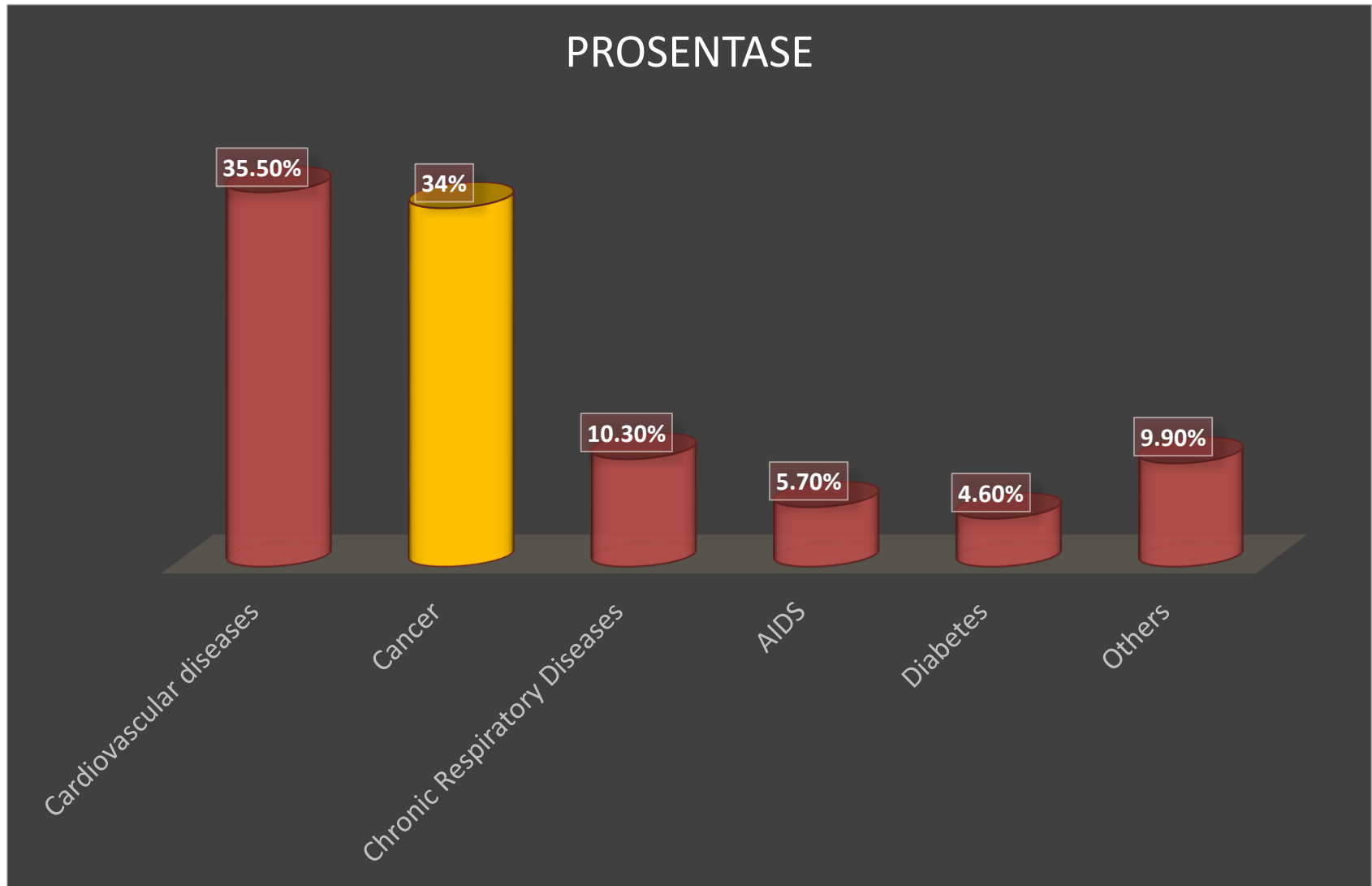
MYTH 9: Palliative care is only for people dying of cancer.



**FACT:** Palliative care can benefit patients and their families from the time of diagnosis of any life-limiting illness.

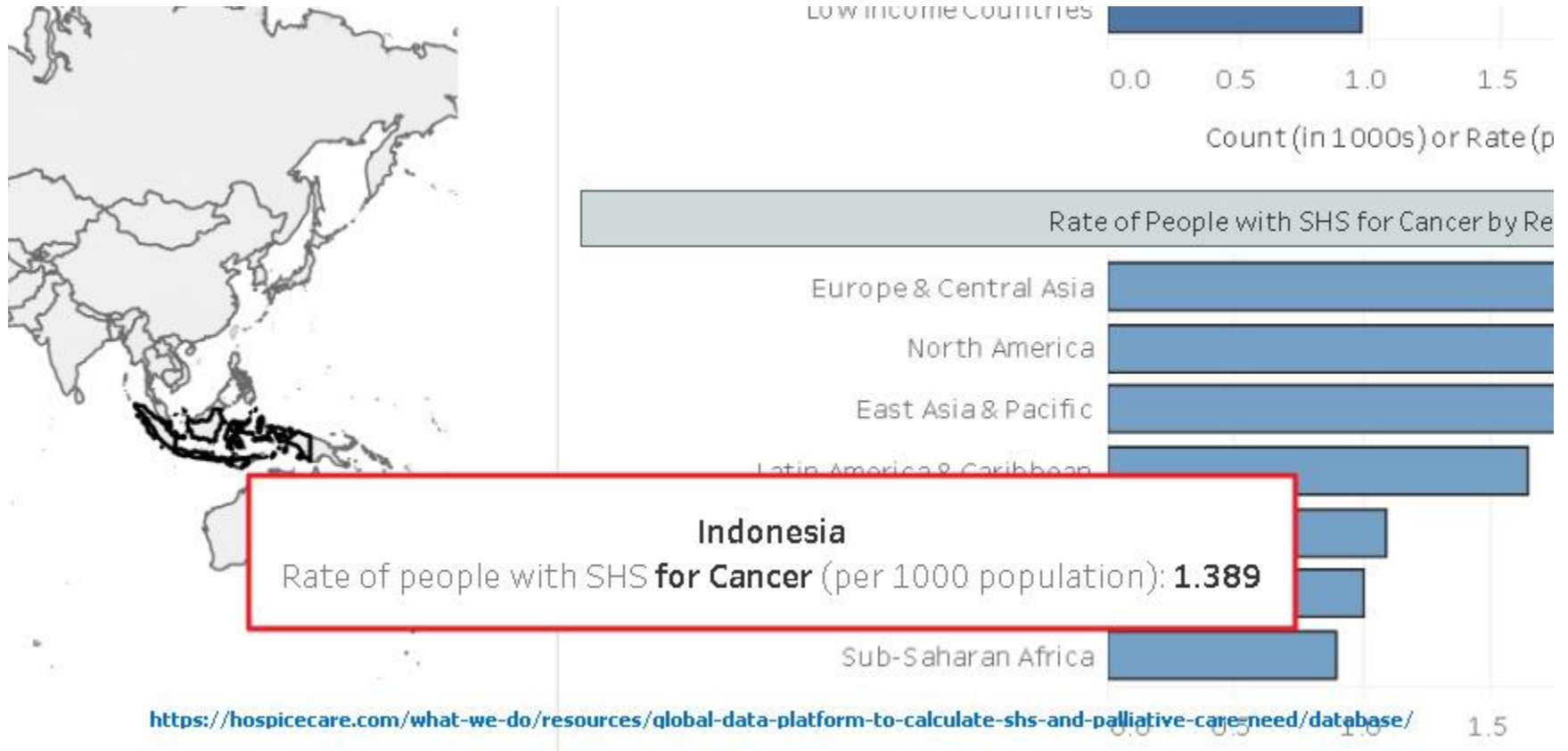
[https://www.nygh.on.ca/data/2/rec\\_docs/3244\\_Palliative\\_Care\\_Myths\\_and\\_Facts\\_Infographic\\_May2018.pdf](https://www.nygh.on.ca/data/2/rec_docs/3244_Palliative_Care_Myths_and_Facts_Infographic_May2018.pdf)

## PALLIATIVE CARE IS REQUIRED FOR A WIDE RANGE OF DISEASES



<http://www.who.int/en/news-room/fact-sheets/detail/palliative-care>

# POPULASI PENDERITA KANKER DI INDONESIA (2015)





# PELAYANAN KESEHATAN

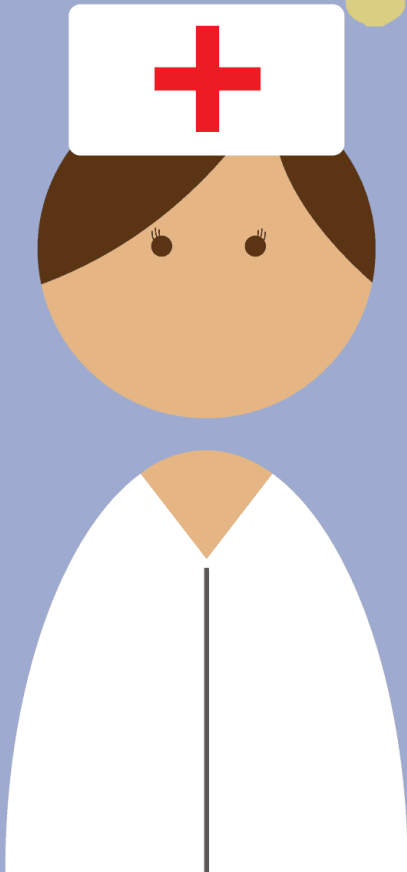
Promotif  
Preventif

Kuratif

Rehabilitatif

Suportif

**Paliatif**



# HISTORY OF PALLIATIVE CARE



**Dame Mary Cicely Saunders**

(22 Juni 1918 - 14 Juli 2005)

**TOTAL PAIN**

**MODERN HOSPICE**

**(1960)**

<http://www.case-stories.org/total-pain-and-social-suffering/>



**dr. Balfour Mount**

Born 14 April 1939

Urological surgeon

Father of Canada's

palliative care

movement

**PALLIATIVE**

*Palliare (Bahasa Latin) = to cloak, cover*

jubah, mantel

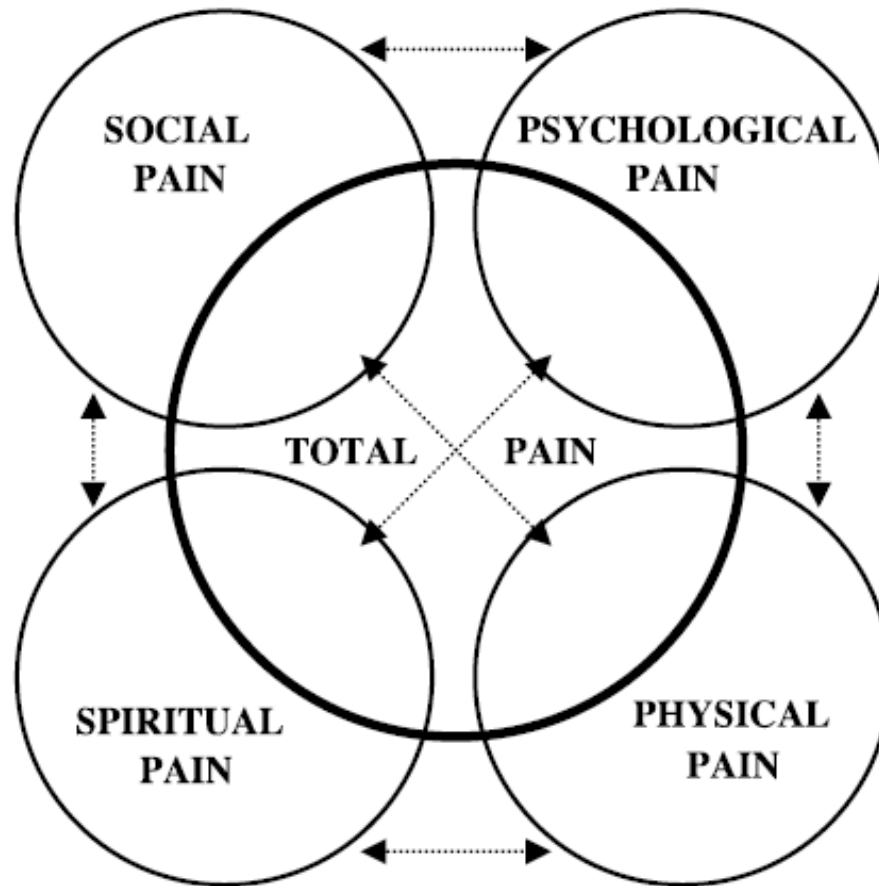




**Butterflies** are known as a symbol of transformation, hope, life, and spirit. Hospices across the country hold butterfly releases to help those who are grieving, remember and honor their loved ones. Another way hospice helps care and nurture their families and the communities they serve.

<https://www.facebook.com/NHPCO/posts/butterflies-are-known-as-a-symbol-of-transformation-hope-life-and-spirit-hospice/10155750819413907/>

# TOTAL PAIN



*Figure 1. The total pain experience: an interactive model.*

# **WHO Definition of Palliative Care**

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.





The **holistic approach** looks at problems in four groups:

- **Physical** – symptoms (complaints),  
eg pain, cough, tiredness, fever
- **Psychological** – worries, fears,  
sadness, anger
- **Social** – needs of the family, issues of  
food, work, housing and relationships
- **Spiritual** – questions of the meaning of  
life and death, the need to be at peace.

# Quality of Life (QoL)

**Kualitas hidup (QoL)** didefinisikan sebagai persepsi individu tentang posisi mereka dalam kehidupan dalam konteks budaya dan sistem nilai di mana mereka hidup dan dalam kaitannya dengan tujuan, harapan, standar, dan kekhawatiran mereka. Ini adalah konsep luas yang dipengaruhi secara kompleks oleh kesehatan fisik seseorang, keadaan psikologis, tingkat kemandirian, hubungan sosial, dan hubungan mereka dengan ciri-ciri menonjol dari lingkungan mereka.

### **Physical**

Functional Ability  
Strength/Fatigue  
Sleep & Rest  
Nausea  
Appetite  
Constipation  
Pain  
Dyspnea

### **Psychological**

Anxiety  
Depression  
Enjoyment/Leisure  
Pain/Dyspnea Distress  
Happiness  
Fear  
Cognition  
Attention

Quality of Life

### **Social**

Financial Burden  
Caregiver Burden  
Roles and Relationships  
Affection/Sexual Function  
Appearance

### **Spiritual**

Hope  
Suffering  
Meaning of Pain/Dyspnea  
Religiosity  
Transcendence

Adapted from Ferrell et al., 1991

# KEPUTUSAN MENTERI KESEHATAN REPUBLIK INDONESIA

NOMOR : 812/Menkes/SK/VII/2007  
TENTANG

**KEBIJAKAN PERAWATAN PALIATIF**

MENTERI KESEHATAN REPUBLIK INDONESIA

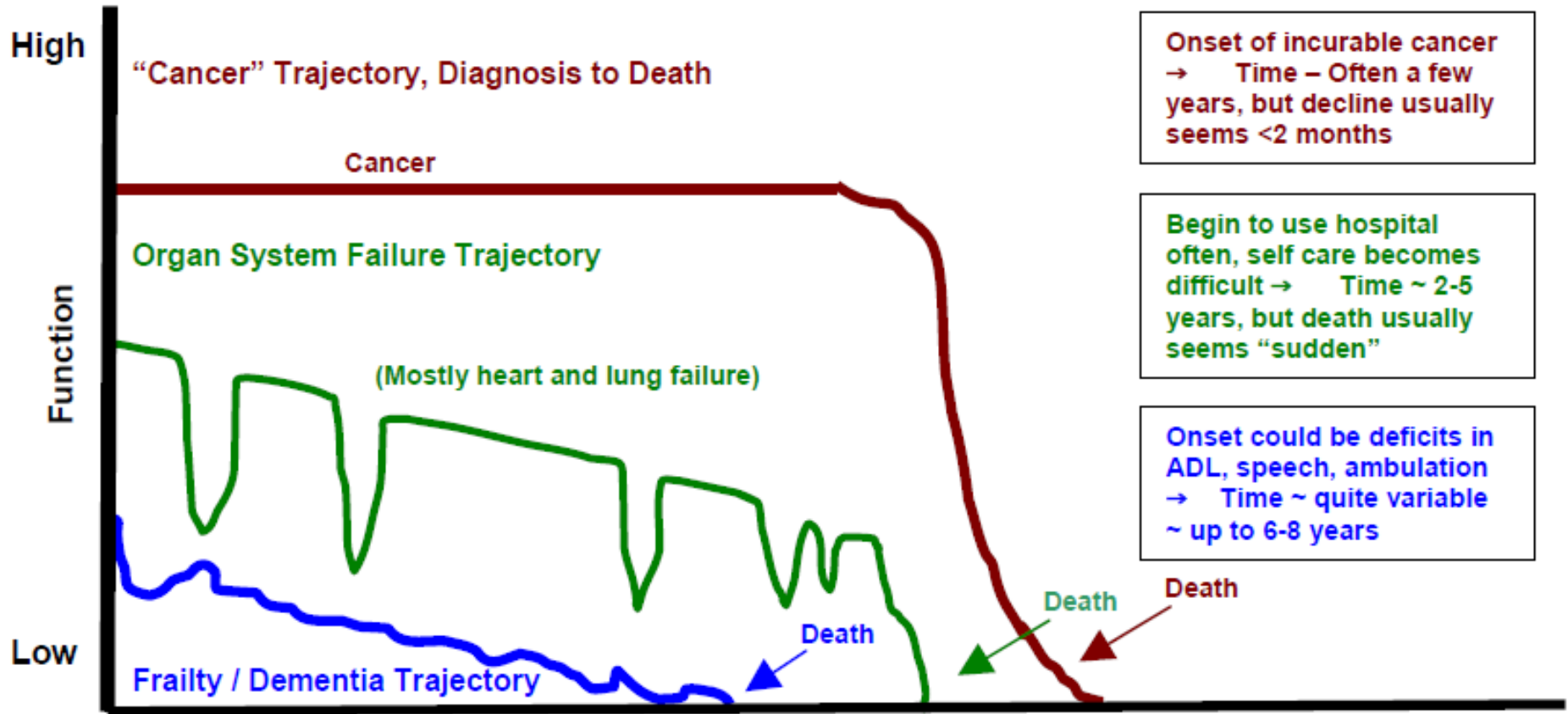
**Pada tanggal : 19 Juli 2007**



Dr. dr. SITI FADILAH SUPARI Sp.JP (K)

<http://dinkes.surabaya.go.id/portal/files/kepmenkes/skmenkes812707.pdf>

# LINTASAN SAKIT



## ILLNESS TRAJECTORY



Department of Health, Western Australia. Palliative Care Model of Care.  
Perth: WA Cancer & Palliative Care Network, Department of Health, Western  
Australian; 2008.



## Terminal Illness (Cancer)

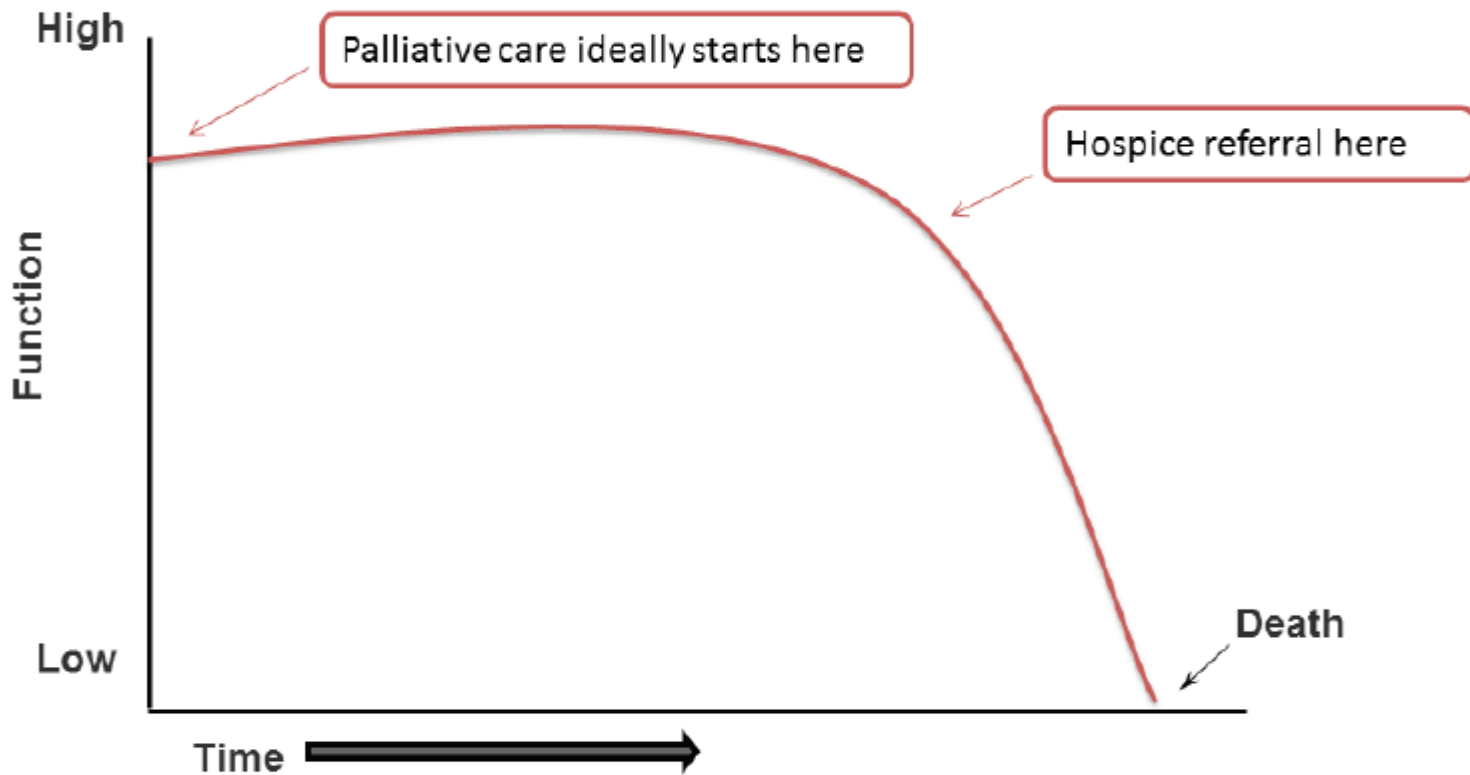
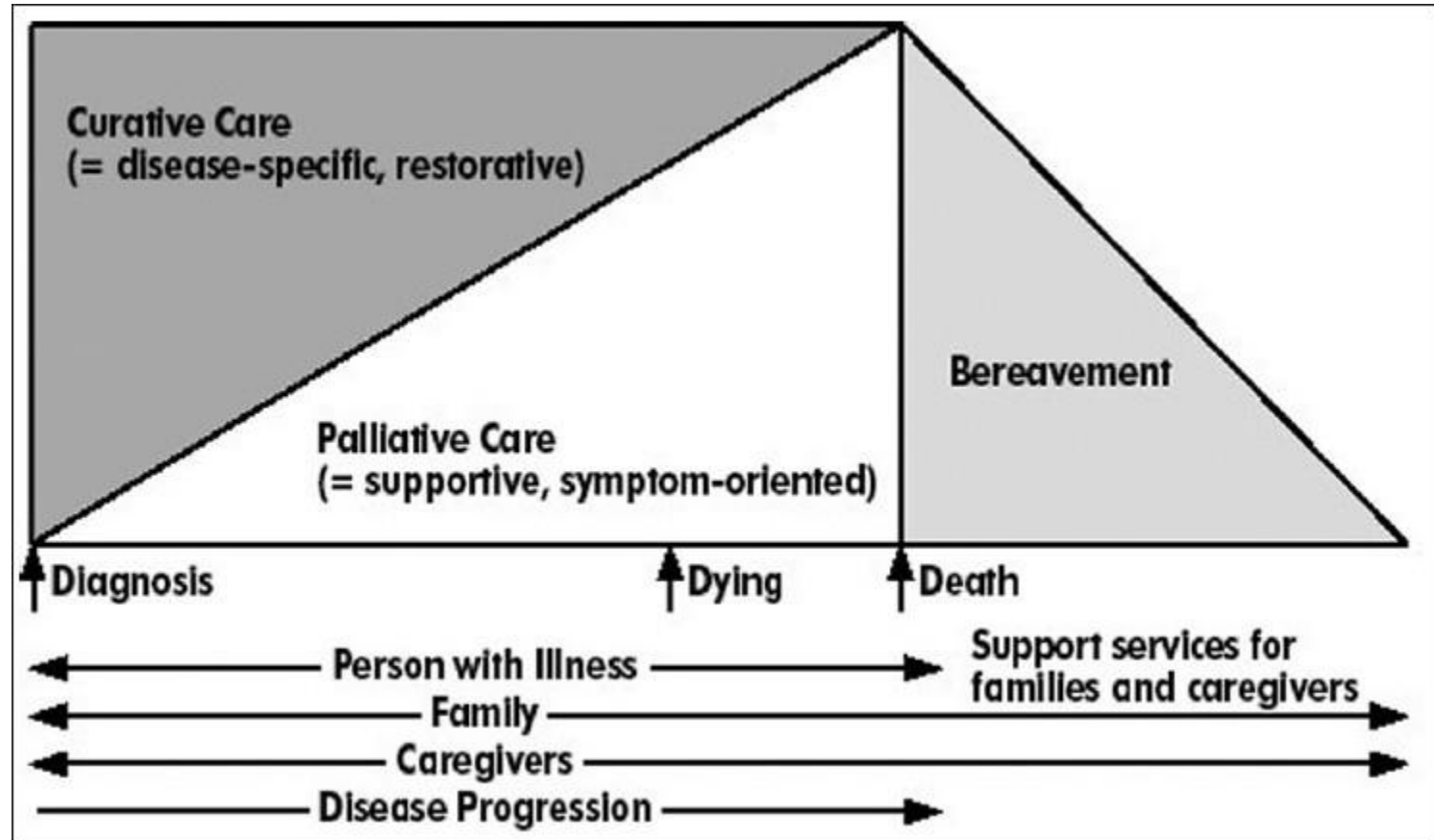


Figure 2: Terminal Disease Trajectory. Adapted with permission from Lynn, 2004.

# MODEL BARU PERAWATAN PALIATIF



[http://www.jpalliativecare.com/articles/2010/16/3/images/IndianJPalliatCare\\_2010\\_16\\_3\\_107\\_7363](http://www.jpalliativecare.com/articles/2010/16/3/images/IndianJPalliatCare_2010_16_3_107_7363)

9\_f1.jpg

PATIENTS ARE  
**'APPROACHING THE END OF LIFE'**  
WHEN THEY ARE LIKELY TO DIE  
WITHIN THE NEXT 12 MONTHS.

[https://web.archive.org/web/20101130194228/https://www.gmc-uk.org/static/documents/content/End\\_of\\_life.pdf](https://web.archive.org/web/20101130194228/https://www.gmc-uk.org/static/documents/content/End_of_life.pdf)

# THE END OF LIFE

## THE END OF LIFE

## THE DYING PHASE

At risk of dying in  
6 – 12 months, but  
may live for years

**MONTHS**  
2 – 9 months

**SHORT WEEKS**  
1 – 8 weeks

**LAST DAYS**  
2 – 14 days

**LAST HOURS**  
0 – 48 hours

**DISEASE(S)  
RELENTLESS**  
Progression is less  
reversible  
Treatment  
benefits are  
waning

**CHANGE  
UNDERWAY**  
Benefit of  
treatment less  
evident  
Harms of  
treatment less  
tolerable

**RECOVERY LESS  
LIKELY**  
The risk of death  
is rising

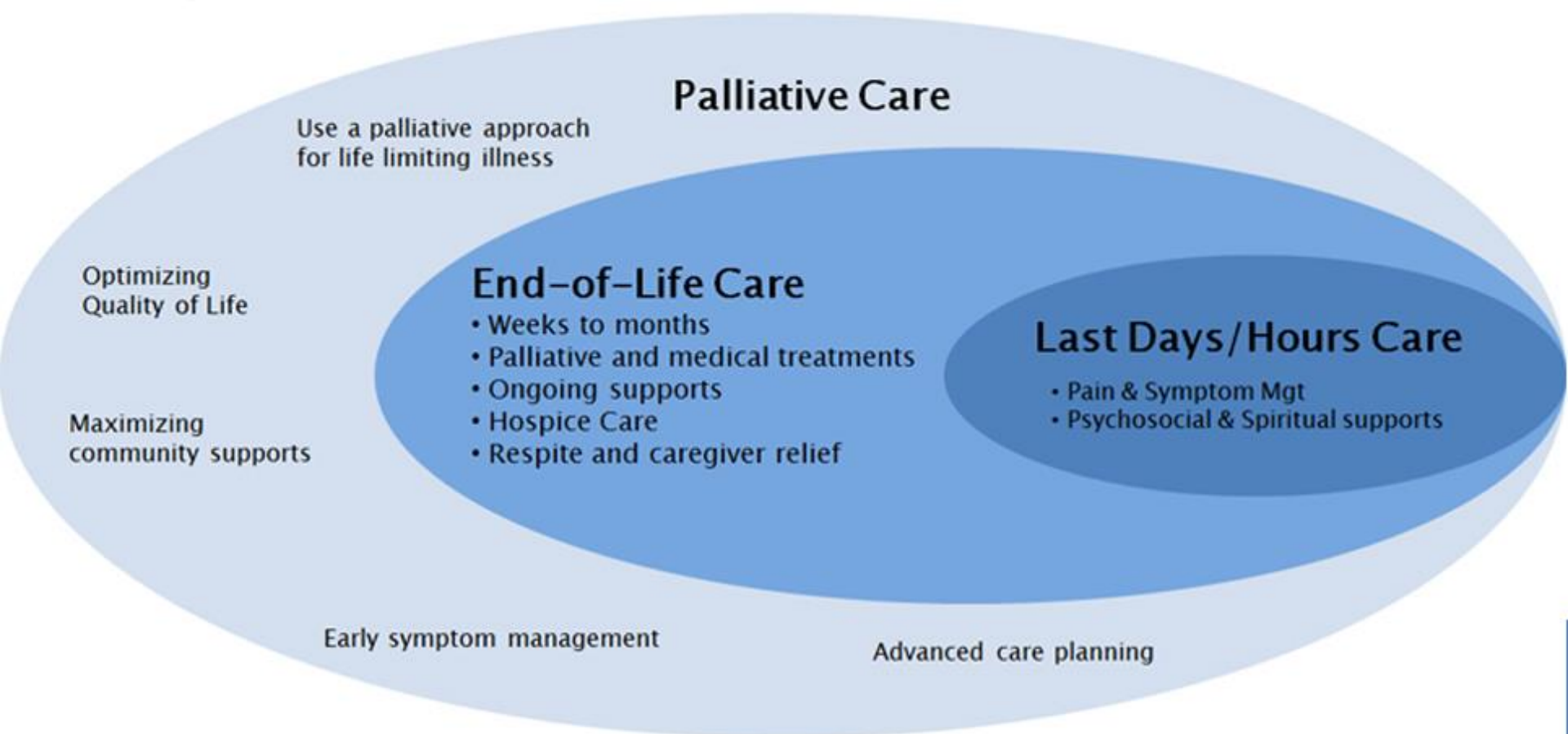
**DYING  
BEGINS**  
Deterioration is  
weekly/daily

**ACTIVELY  
DYING**  
The body is  
shutting down  
The person is  
letting go

**Figure 1.5** Time frames in the dying process<sup>1</sup>

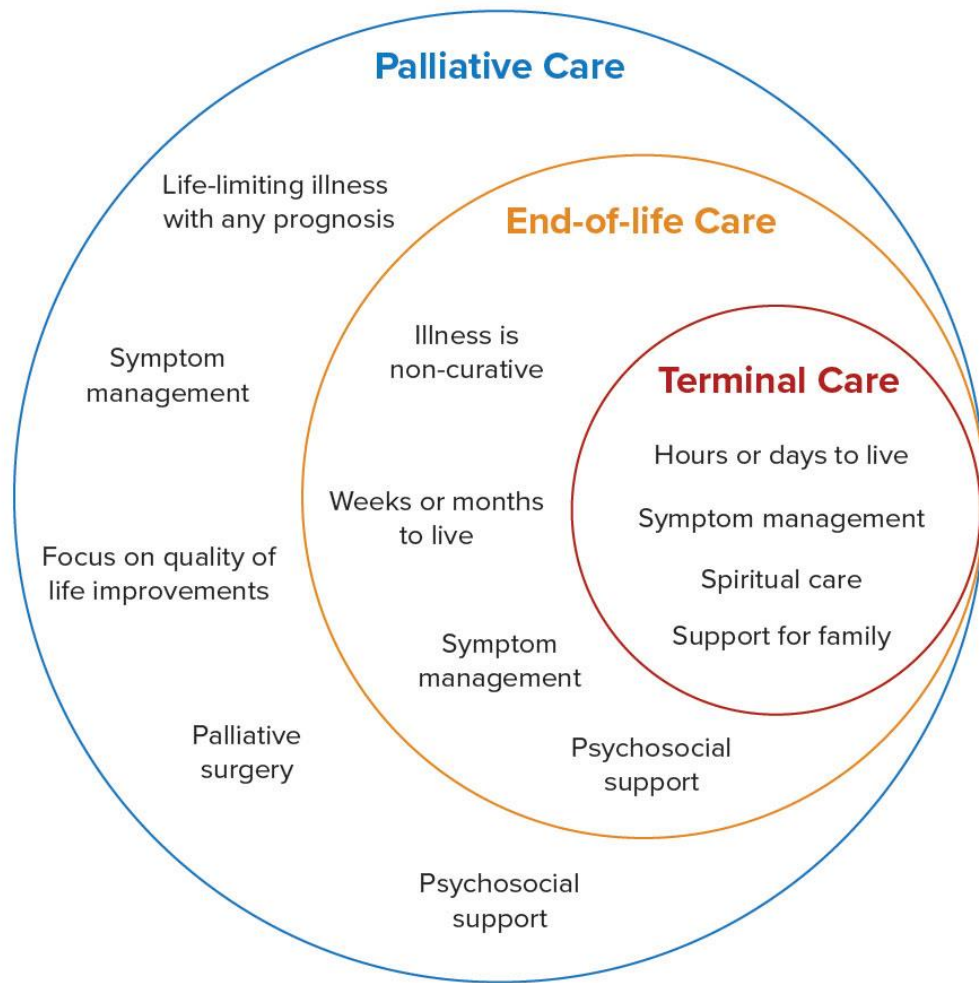
Reproduced from *Independent Review of the Liverpool Care pathway: More Care, Less Pathway*, Williams Lea, London, UK, © Crown Copyright 2013, licensed under the Open Government Licence v.2.0.





<https://www.interiorhealth.ca/YourCare/PalliativeCare/PublishingImages/whatispalliative-lg.jpg>





**Terminal Care**

**End-of-life Care**

**Palliative Care**

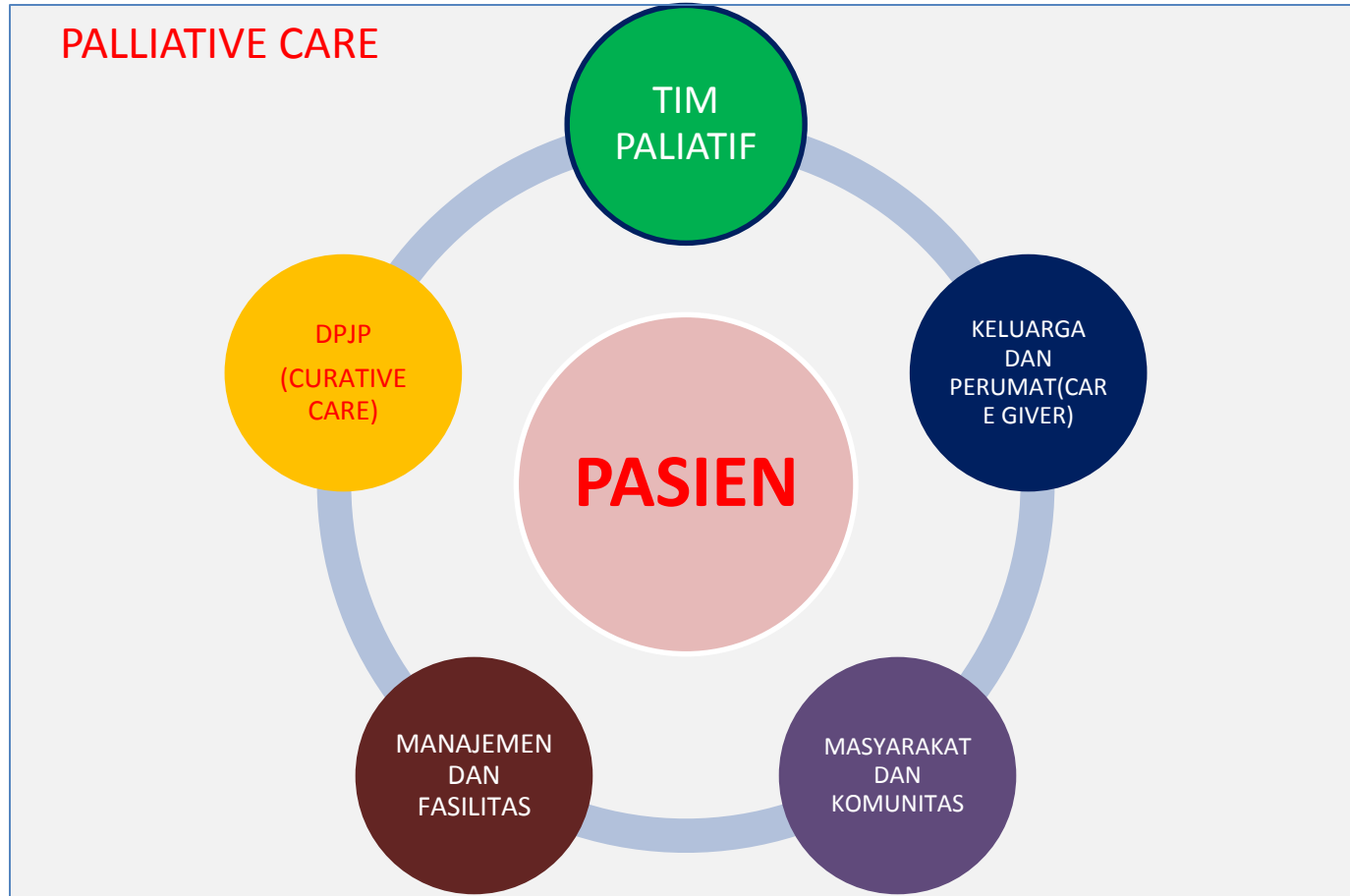
Diagnosis ←————→ Death

## End-Stage Indicators

### Cancer Diagnoses

1. Disease with distant metastases at presentation OR
2. Progression from an earlier stage of disease to metastatic disease with either:
  - a continued decline in spite of therapy
  - patient declines further disease directed therapy

# INTEGRASI PERAWATAN PALIATIF



## KERJASAMA TIM

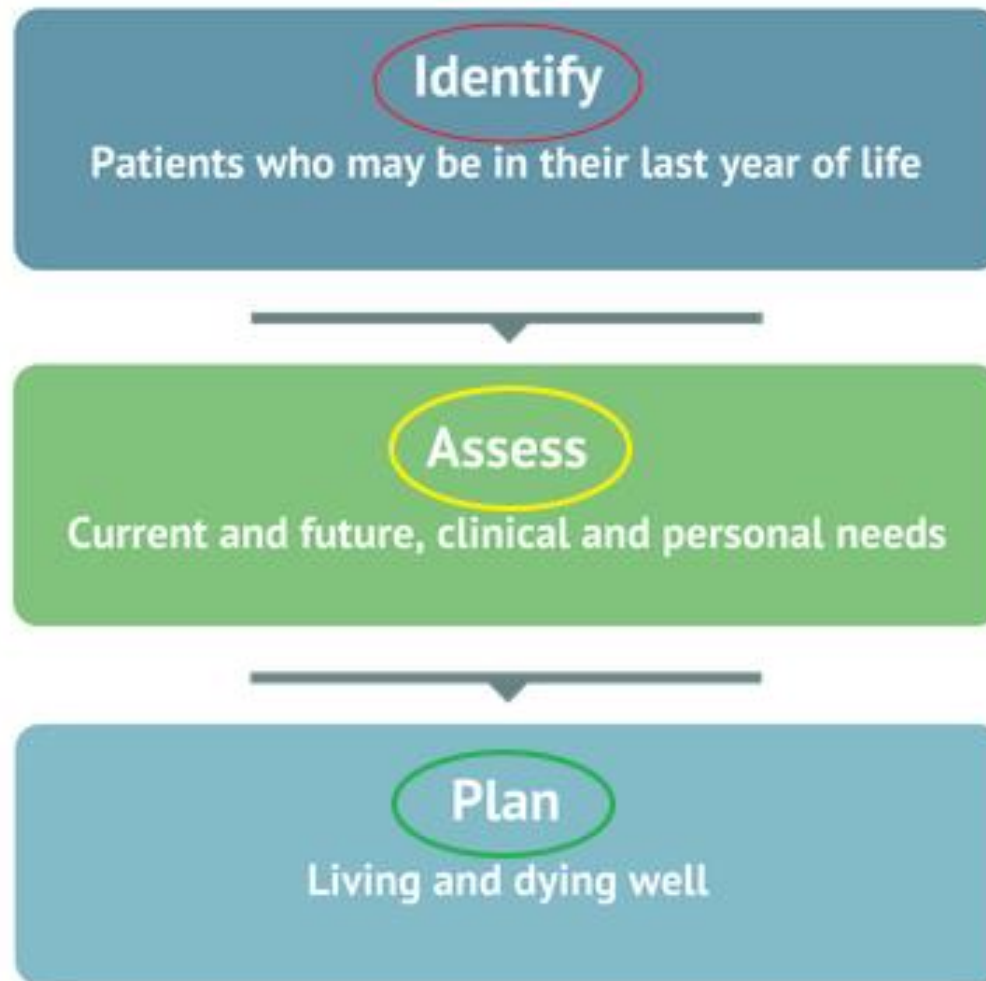


# TIM PERAWATAN PALIATIF RUMAH SAKIT

- Dokter
- Perawat
- Fisioterapis
- Farmasis
- Rohaniawan
- Pekerja sosial

Multidisipliner  
Kolaborasi  
Koordinatif

# PROVIDING A PALLIATIVE APPROACH TO CARE



<https://library.nshealth.ca/PalliativeCare>

# Identify if the patient would benefit from palliative care earlier in their illness trajectory

Three **triggers** that suggest that patients could benefit from a palliative care approach:

1. **The Surprise Question:** 'Would you be surprised if the patient were to die in the next year?'
2. **General indicators of decline:** deterioration, advanced disease, decreased response to treatment, choice for no further disease modifying treatment.
3. **Specific clinical indicators** related to certain conditions.

# Ask the Surprise Question


Would you be surprised if the patient were to die in next year, months, weeks, days?

**YES**  
☐

**NO**  
☒

**listen  
to your  
intuition -  
it's on  
your side.**





**Bear in mind that even  
doctors with long  
experience tend to  
over-estimate  
prognosis.**

<https://static.scientificamerican.com>

**Do they have  
General Indicators  
of Decline?**

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Do they have  
Specific Clinical  
Indicators?



## Cancer

- **Functional ability deteriorating** due to progressive cancer.
- **Too frail** for cancer treatment or treatment is for symptom control.

# Tool



**Supportive and Palliative Care  
Indicators Tool (SPIC<sup>TM</sup>)**



**The SPIC<sup>TM</sup> is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.**

**Look for any general indicators of poor or deteriorating health.**

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

**Look for clinical indicators of one or multiple life-limiting conditions.**

Cancer	Heart/ vascular disease	Kidney disease
Functional ability deteriorating due to progressive cancer.	Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.	Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
Too frail for cancer treatment or treatment is for symptom control.	Severe, inoperable peripheral vascular disease.	Kidney failure complicating other life limiting conditions or treatments.
<b>Dementia/ frailty</b>	<b>Respiratory disease</b>	<b>Liver disease</b>
Unable to dress, walk or eat without help.	Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.	Cirrhosis with one or more complications in the past year:
Eating and drinking less; difficulty with swallowing.	Persistent hypoxia needing long term oxygen therapy.	• diuretic resistant ascites
Urinary and faecal incontinence.	Has needed ventilation for respiratory failure or ventilation is contraindicated.	• hepatic encephalopathy
Not able to communicate by speaking; little social interaction.		• hepatorenal syndrome
Frequent falls; fractured femur.		• bacterial peritonitis
Recurrent febrile episodes or infections; aspiration pneumonia.		• recurrent variceal bleeds
<b>Neurological disease</b>	<b>Other conditions</b>	Liver transplant is not possible.
Progressive deterioration in physical and/or cognitive function despite optimal therapy.	Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.	
Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.		
Recurrent aspiration pneumonia; breathless or respiratory failure.		
Persistent paralysis after stroke with significant loss of function and ongoing disability.		

**Review current care and care planning.**

- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.

Please register on the SPIC<sup>TM</sup> website ([www.spict.org.uk](http://www.spict.org.uk)) for information and updates.

SPIC<sup>TM</sup>, April 2019

## SPIC<sup>TM</sup>-App



<https://www.spict.org.uk/spictapp/>

<https://www.spict.org.uk/>



Assess the person's current and future needs and preferences across all domains of care.

### Screening Tools

- **Edmonton Symptom Assessment System** (ESAS-r)
- **Palliative Performance Scale** (PPSv2)

<https://www.ontariopalliativecarenetwork.ca/en/node/31896>

# Edmonton Symptom Assessment System: (revised version) (ESAS-R)

**Cancer Care Ontario**  
**Action Cancer Ontario**

Edmonton Symptom Assessment System:  
(revised version) (ESAS-R)

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
<hr/>												
No Tiredness (Tiredness = lack of energy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
<hr/>												
No Drowsiness (Drowsiness = feeling sleepy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
<hr/>												
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
<hr/>												
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
<hr/>												
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
<hr/>												
No Depression (Depression = feeling sad)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
<hr/>												
No Anxiety (Anxiety = feeling nervous)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
<hr/>												
Best Wellbeing (Wellbeing = how you feel overall)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
<hr/>												
No _____ Other Problem (for example constipation)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____

Patient's Name \_\_\_\_\_

Date \_\_\_\_\_ Time \_\_\_\_\_

Completed by (check one):

- ☐ Patient  
☐ Family caregiver  
☐ Health care professional caregiver  
☐ Caregiver-assisted

BODY DIAGRAM ON REVERSE SIDE

ESAS-r  
Revised: 2015

## ***Palliative Performance Scale (PPSv2)***

***version 2***

<b>PPS Level</b>	<b>Ambulation</b>	<b>Activity &amp; Evidence of Disease</b>	<b>Self-Care</b>	<b>Intake</b>	<b>Conscious Level</b>
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity <i>with</i> Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Stable  
70 – 100 %

Transitional  
40 – 60%

End-of-Life  
0 -30 %

[www.victoriahospice.org/sites/default/files/pps\\_english.pdf](http://www.victoriahospice.org/sites/default/files/pps_english.pdf)





## CONTOH KASUS

Pasien sangat lemah dan tetap berada di kursi beberapa jam sehari. Sisa waktu, dia sedang di tempat tidur. Dia memiliki penyakit lanjut dan membutuhkan bantuan yang hampir lengkap dengan perawatan diri dan makanan. Ia mengalami penurunan asupan makanan, dengan beberapa camilan kecil yang kebanyakan tetap belum selesai. Dia memiliki asupan cairan yang cukup. Pasien mengantuk (*DROWSY*) tapi tidak bingung (*CONFUSED*).

## BERAPA PPS PASIEN TERSEBUT?

ePrognosis - Palliative Performance X +

University of California San Francisco

# ePrognosis

## Palliative Performance Scale

- Population: Hospitalized patients with palliative care consultation
- Outcome: Median Survival in days
- Scroll to the bottom for more detailed information

### Risk Calculator

1. How ambulatory is this patient?

Select ▼

<https://eprognosis.ucsf.edu/pps.php?p=palliative>



# Family Meeting

INFORMATION

**BREAKING BAD NEWS**

FAMILY SUPPORT

ADVANCED CARE PLANNING



- VALUES
- WISHES
- BELIEFS
- PREFERENCES
- GOALS

- **VALUES**
- **WISHES**
- **BELIEFS**
- **PREFERENCES**
- **GOALS**

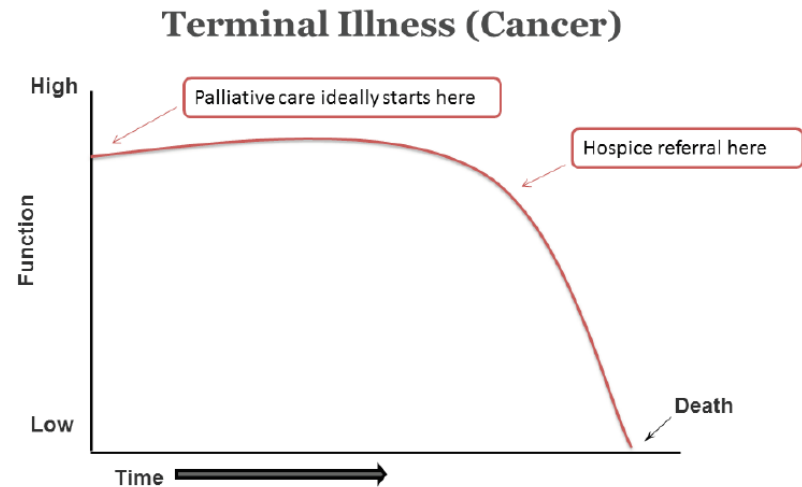


Figure 2: Terminal Disease Trajectory. Adapted with permission from Lynn, 2004.

**NILAI – HARAPAN – KEYAKINAN - PREFERENSI - TUJUAN**



# BREAKING BAD NEWS

- Persiapkan dan Rencanakan
- Cari Tahu Apa yang Pasien dan Keluarga Tahu dan Ingin tahu
- Dukungan Emosi (Support Mental Pasien dan Keluarga)
- Membuat Rekomendasi
- Resolusi konflik



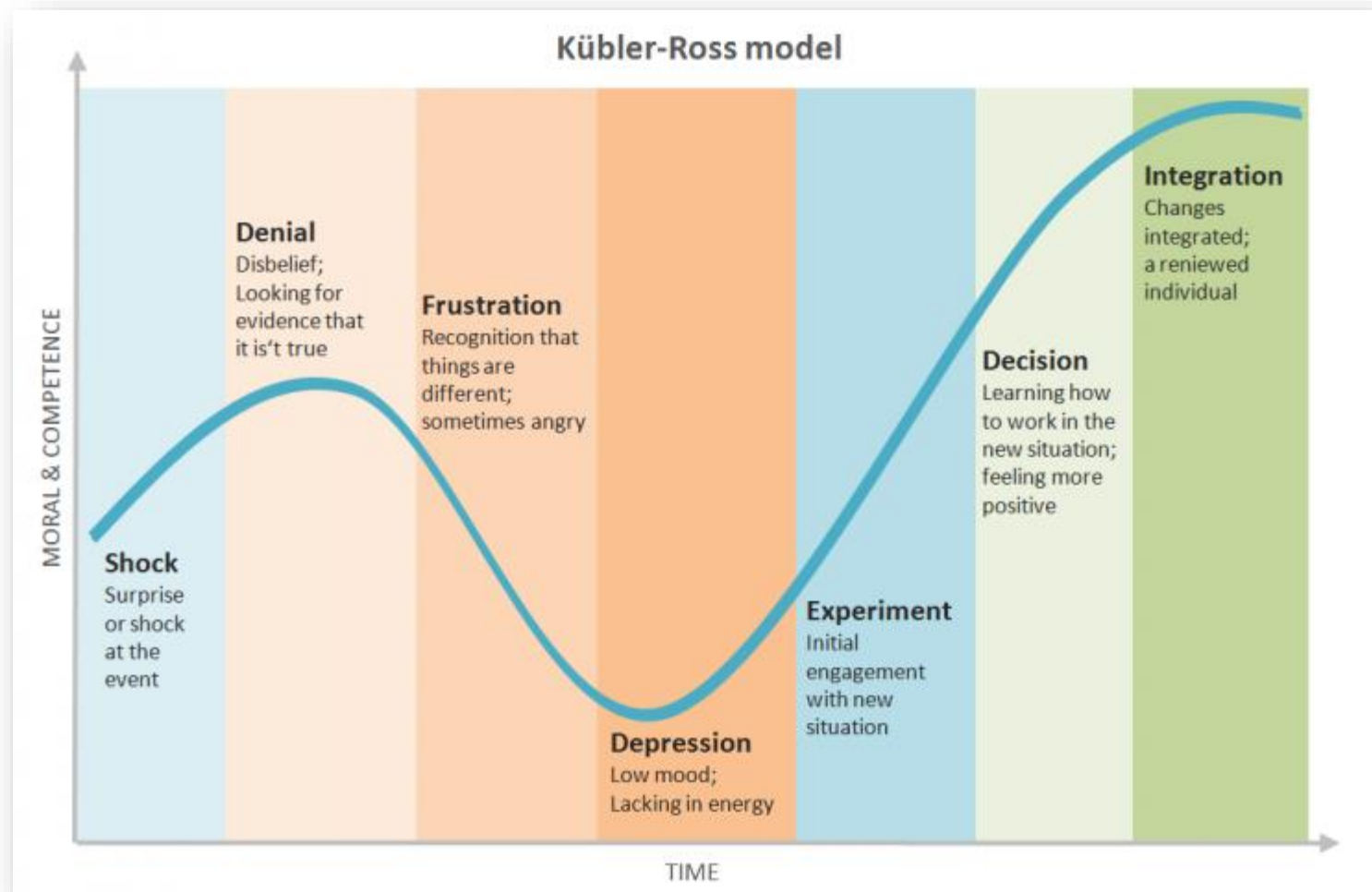
Memberikan informasi **sesuai** kebutuhan pasien dan keluarga.

- Berikan pasien kesempatan untuk membahas **harapan-harapannya**, atau disisi lain menghargai untuk tidak membahasnya jika pasien tidak menginginkannya.
- Berikan informasi secara **bertahap** sesuai yang diinginkan pasien.
- Gunakan bahasa yang **jelas dan mudah** dimengerti serta menghindari penggunaan istilah-istilah medis.
- Menjadi **pendengar** yang baik dan tanyakan kembali untuk memperjelas maksud pernyataannya.

- Jelaskan mengenai ketidakpastian dan keterbatasan dari **prognosis** dan **masa akhir kehidupan**.
- **Hindari memberikan batasan waktu kecuali kondisi pasien sudah terminal**
- Perhatikan juga hal-hal yang diperlukan oleh pelaku rawat. **Pertimbangkan pertemuan terpisah antara pasien dengan pelaku rawat bila dibutuhkan.**
- Berikan informasi dan pendekatan yang konsisten kepada setiap anggota keluarga pasien, pasien dan tim paliatif yang merawat.
- **Minimalkan penggunaan kata-kata ‘meninggal’ dan ‘sekarat’ dalam diskusi.**



# TAHAPAN PSIKOLOGIS PASIEN DALAM MENGHADAPI KONDISI SAKIT



# The five stages are: **DABDA**

**Denial** - "It can't be happening."

**Anger** - "Why me?"

**Bargaining** - "Just let me live to see my grandchild born."

**Depression** - "God please don't take me away from my family."

**Acceptance** - a state in which there may be an intense longing for death.

# Ethical Principles

- **Autonomy:** Making one's own decision
- **Beneficence:** Intending to do good
- **Nonmaleficence:** Intending to do no harm
- **Justice:** Providing equal access

1. *A person requires clear information to make autonomous decisions.*
2. *Beneficence intends best possible treatment for the individual.*
3. *Beneficence infers a balancing of possible benefits and possible risks or harms.*
4. *Beneficence requires clinicians to keep up to date with current knowledge.*
5. *Withholding or withdrawing treatment is ethically and legally acceptable if the treatment is futile.*
6. *A Living Will or Advance Directive provides guidance on a person's preferences for care.*

<http://www.cmej.org.za/index.php/cmej/article/view/2181/1877>

# ETHICAL ISSUES IN PALLIATIVE CARE

- ☐ Withholding and Withdrawing Treatment
- ☐ How Much Care?
- ☐ Planning Care
- ☐ The Doctrine of Double Effect
- ☐ Cardiopulmonary Resuscitation (CPR)
- ☐ Palliative Sedation



Plan and collaborate ongoing care to address needs identified during the assessment. This includes prompt management of symptoms and coordination with other care providers.

<https://www.ontariopalliativecarenetwork.ca/en/node/31896>

# Collaborative Care Plans:

**STABLE PHASE**  
**(PPS 70—100%)**

**TRANSITIONAL PHASE**  
**(PPS 40—60%)**

**END OF LIFE PHASE**  
**(PPS 0—30%)**

<http://www.mhpcn.net/following-provides-local-relevance-each-collaborative-care-plan>

# 11 SYMPTOMS

1. Pain
2. Anorexia
3. Nausea and vomiting
4. Constipation
5. Diarrhoea
6. Dyspnea
7. Fatigue
8. Delirium
9. Depression
10. Anxiety
11. Respiratory tract secretions

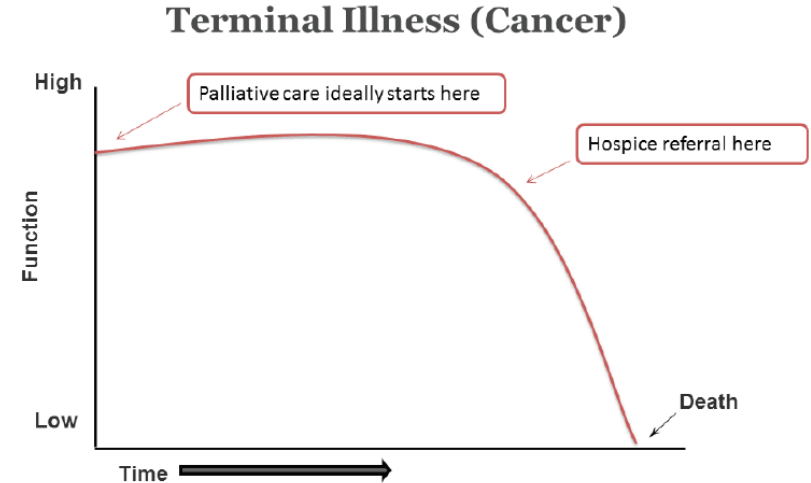


Figure 2: Terminal Disease Trajectory. Adapted with permission from Lynn, 2004.





**Edmonton Symptom Assessment System:**  
(revised version) (ESAS-R)

**PAIN**

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
---------	---	---	---	---	---	---	---	---	---	---	----	---------------------

**TIREDNESS**

No Tiredness (Tiredness = lack of energy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
--	---	---	---	---	---	---	---	---	---	---	----	--------------------------

**DROWSINESS**

No Drowsiness (Drowsiness = feeling sleepy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
--	---	---	---	---	---	---	---	---	---	---	----	---------------------------

**NAUSEA**

No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
-----------	---	---	---	---	---	---	---	---	---	---	----	-----------------------

**LACK OF APPETITE**

No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
---------------------	---	---	---	---	---	---	---	---	---	---	----	---------------------------------

**SHORTNESS OF BREATH**

No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
------------------------	---	---	---	---	---	---	---	---	---	---	----	------------------------------------

**DEPRESSION**

No Depression (Depression = feeling sad)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
---	---	---	---	---	---	---	---	---	---	---	----	---------------------------

**ANXIETY**

No Anxiety (Anxiety = feeling nervous)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
---	---	---	---	---	---	---	---	---	---	---	----	------------------------

**WELLBEING**

Best Wellbeing (Wellbeing = how you feel overall)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
--	---	---	---	---	---	---	---	---	---	---	----	--------------------------

**OTHER PROBLEM**

No _____ Other Problem (for example constipation)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____
--	---	---	---	---	---	---	---	---	---	---	----	----------------------

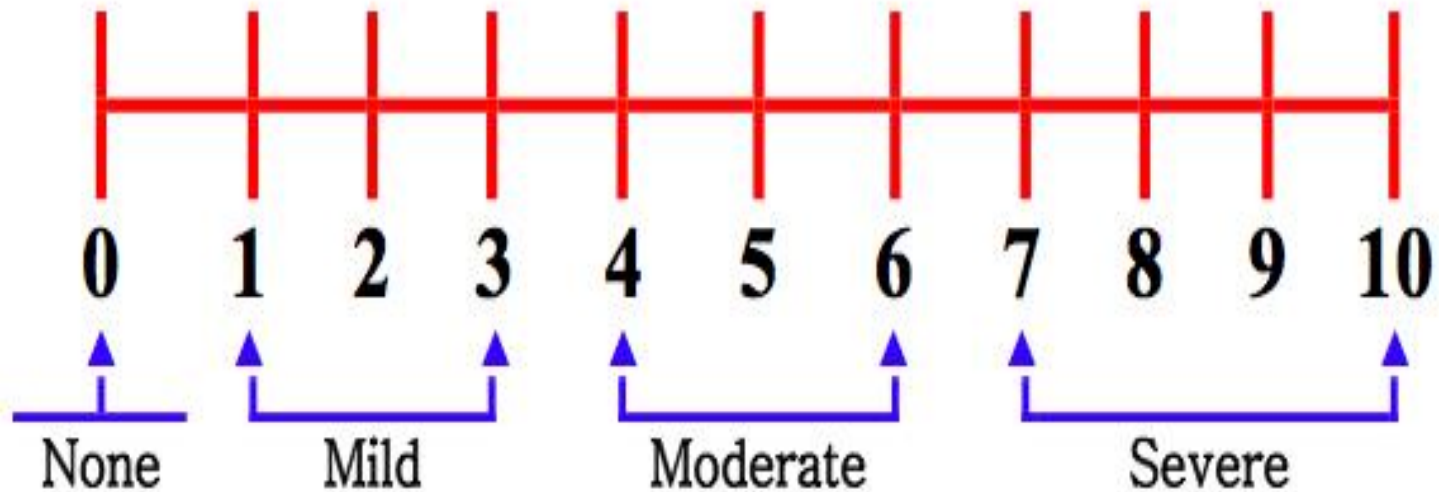
# nyeri



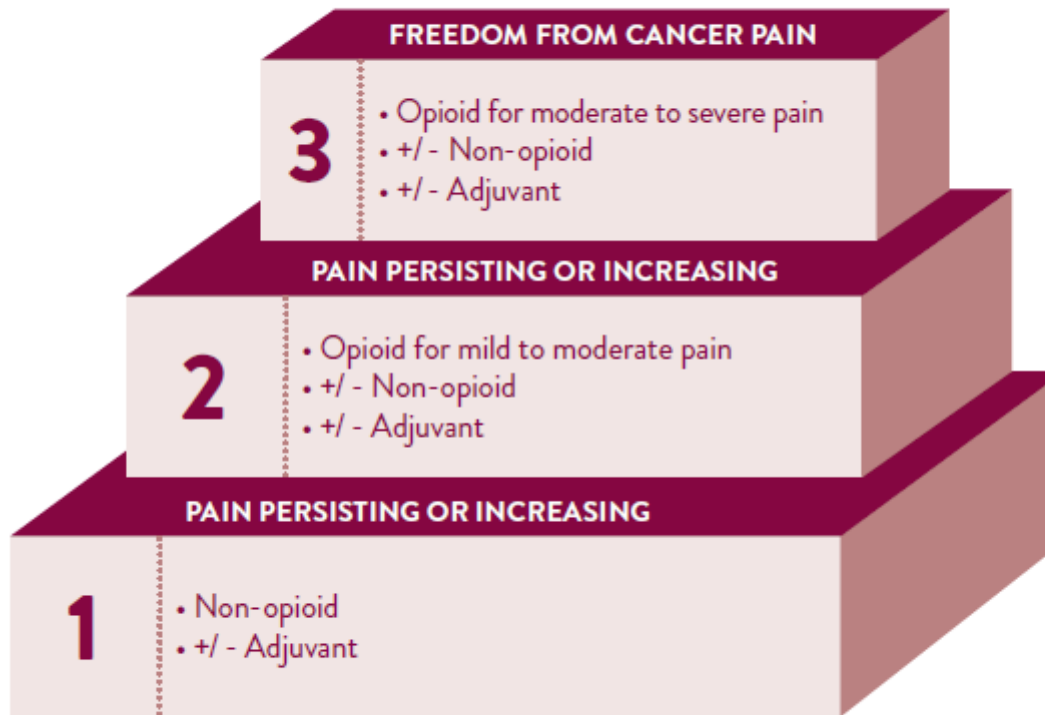
Nyeri adalah keluhan yang paling banyak dijumpai pada pasien kanker stadium lanjut.



## Skala Angka (Numeric Rating Scale)



## THREE-STEP ANALGESIC LADDER



The concept of a ladder explains the need for pain assessment and for appropriate management of pain based on the severity of pain.

<https://www.who.int/ncds/management/en/>

# PENGUNAAN ANALGESIK UNTUK TATALAKSANA NYERI

		ANALGESIK	OBAT PILIHAN	OBAT LAIN
STEP 1	Nyeri	Non opioid		
Ringan		Adjuvan		
1,2,3				
STEP 2	Nyeri	Opioid lemah	Codein	Tramadol
Sedang	menetap atau	Non opioid		
4,5,6	meningkat	Adjuvan		
STEP 3	Nyeri	Opioid kuat	Morfin	Fentanil
Berat	menetap atau	Non opioid		
7,8,9,10	meningkat	Adjuvan		

## **Pain**

**Recommended medicines for inclusion:**

# **IBUPROFEN and MORPHINE**

**Recommended formulations for inclusion:**

Ibuprofen:

Oral liquid: 200 mg/5 mL

Tablet: 200 mg; 400 mg; 600 mg.

Morphine:

Granules (modified release) (to mix with water): 20 mg; 30 mg; 60 mg; 100 mg; 200 mg.

Injection: 10 mg/mL

Oral liquid: 10 mg/5 mL

Tablet (controlled release): 10 mg; 30 mg; 60 mg.

Tablet (immediate release): 10 mg.

**Tata laksana rehabilitasi medik non  
medikamentosa** pada nyeri kanker paliatif, yakni :

pemberian modalitas TENS/interferensial ,  
superficial heating, massage, relaksasi, breathing  
exercise, muscle and joint exercise, propper body  
positioning, dan pada kasus metastase di tulang  
belakang, diberikan spinal ortose.

# anoreksia - kaheksia



Anorexia pada pasien stadium lanjut sering kali bukan menjadi keluhan pasien tetapi keluhan keluarga.

Hilangnya nafsu makan sering dihubungkan dengan rasa penuh dan cepat kenyang. Anorexia biasanya merupakan gejala

**Anorexia-Cachexia Sindrom** atau kondisi yang lain.





## **Anorexia (appetite loss)**

Recommended medicine for inclusion:

### **DEXAMETHASONE**

Recommended formulations for inclusion:

Injection: 4 mg/mL in 1-mL ampoule (as disodium phosphate salt)

Oral liquid: 2 mg/5 mL

New recommended formulation for addition:

**Dexamethasone tablet 4mg**

# 7p

- **Preference**
  - **Palatable**
  - **Presentation**
  - **Portions**
  - **Position**
  - **Patience**
  - **Provide**
- *establish likes and dislikes.*
  - *food should be what the person fancies, perhaps with cream/ butter to add calories.*
  - *food should be visually appealing and appetising.*
  - *smaller plates for smaller portions.*
  - *ensure you and the person being assisted are in a comfortable position for eating.*
  - *let the person take their own time.*
  - *good mouth care regularly, whether eating and drinking or not.*

<https://www.rcn.org.uk/-/media/royal-college-of-nursing/documents/publications/2015/june/getting-it-right-every-time.pdf?la=en>

# mual / muntah



Mual dan muntah adalah salah satu keluhan yang sangat mengganggu pasien.

Penyebabnya biasanya lebih dari satu macam.

Mual dapat terjadi terus menerus atau intermiten.



## **Nausea and Vomiting**

**Recommended medicine for inclusion:**

## **METOCLOPRAMIDE**

**Recommended formulations for inclusion:**

Injection: 5 mg (hydrochloride)/mL in 2-mL ampoule.

Oral liquid: 5 mg/5 mL

Tablet: 10 mg (hydrochloride)

## Tata laksana mual dan muntah harus disesuaikan dengan penyebabnya.

- Hiperasiditas menyebabkan mual, rasa pahit dan nyeri lambung Bila sesudah muntah keluhan masih ada, berikan proton pump inhibitor seperti **omeprazole** 20 mg atau **ranitidine** 300 mg PO.
- Mual akibat iritasi mukosa karena pemberian NSAID: omeprazol 20 mg PO.
- Mual akibat kemoterapi atau radiasi: 5-HT3-reseptor antagonis: **ondansetron 4 mg 1-2x/hari**
- Plus dexamethasone 4 mg pagi hari.



# konstipasi



Terdapat berbagai penyebab konstipasi pada pasien dengan penyakit stadium lanjut sbb:

- 1) Diet rendah serat, kekurangan cairan
- 2) Imobilitas
- 3) Tidak segera ke toilet pada saat rasa bab muncul
- 4) Obat: opioid, anti-cholinergic, antacid yang mengandung aluminium, zat besi, antispasmodic, antipsikotik/anxiolitik.
- 5) Obstruksi saluran cerna: faeces, tumor, perlengketan
- 6) Gangguan metabolisme: hiperkalsemia
- 7) Gangguan saraf gastrointestinal, neuropati saraf otonom



## Medikamentosa:

- **Obat untuk mencegah konstipasi harus diberikan pada pasien yang mendapat opioid.** Gunakan laksatif yang mengandung **pelembut faeces dan stimulan peristaltik.**
- Bila konstipasi telah terjadi: bisacodyl 10 mg dan glyserin supositoria. Jangan berikan laxative stimulant pada obstruksi.
- Gunakan laksatif pelembut feses atau osmotik pada obstruksi partial.
- **Jika pemberian laksatif gagal, lakukan *Rectal Touch*.**
  - 1) Jika feses encer, berikan 2 tablet bisacodyl atau microlax
  - 2) Jika feses keras, berikan 2 gliserin supositoria
  - 3) Jika rectum kosong, lakukan foto abdomen



# diare



Diare dapat terjadi karena beberapa sebab, di antaranya adalah adanya infeksi, malabsorpsi, obstruksi partial, karsinoma kolorektal, kompresi tulang belakang, penggunaan antibiotik, kemoterapi atau radiasi, dan kecemasan.





## **Diarrhoea**

**New recommended medicine for  
addition: LOPERAMIDE**

**New recommended formulation for  
addition:**

Loperamide 2mg tablet or capsule



# **Dyspnoea** ***(breathlessness)***

Merasa tidak bisa bernafas!

## **Dyspnoea (breathlessness)**

**Recommended medicine for inclusion:**

## **MORPHINE**

**Recommended formulations for inclusion:**

Granules (modified release) (to mix with water): 20 mg;  
30 mg; 60 mg; 100 mg; 200 mg.

Injection: 10 mg/mL

Oral liquid: 10 mg/5 mL

Tablet (immediate release): 10 mg.

Tablet (controlled release): 10 mg; 30 mg; 60 mg.

# fatigue / kelemahan



Kelemahan umum dan cepat lelah adalah keluhan yang banyak dijumpai pada pasien paliatif.

**Hal ini sangat memengaruhi kualitas hidup pasien.**

Bagi keluarga, timbulnya keluhan ini sering diinterpretasikan bahwa pasien menyerah.



## **Fatigue**

**Recommended medicine for inclusion:**

## **DEXAMETHASONE**

**Recommended formulations for inclusion:**

Injection: 4 mg/mL in 1-mL ampoule (as disodium phosphate salt)

Oral liquid: 2 mg/5 mL

**New recommended formulations for addition:**

Tablet 4mg

# delirium



Delirium adalah kondisi bingung yang terjadi secara akut dan perubahan kesadaran yang muncul dengan perilaku yang fluktuatif. Gangguan kemampuan kognitif mungkin merupakan gejala awal dari delirium.

Delirium sangat mengganggu keluarga karena adanya disorientasi, penurunan perhatian dan konsentrasi, tingkah laku dan kemampuan berfikir yang tidak terorganisir, ingatan yang terganggu dan kadang muncul halusinasi.



## **Delirium (Confusion)**

**Recommended medicine for inclusion:**

### **HALOPERIDOL**

**Recommended formulations for inclusion:**

Injection: 5 mg in 1-mL ampoule.

Oral liquid: 2 mg/mL

Solid oral dosage form: 0.5 mg; 2mg; 5 mg

# depresi



**Harus dibedakan antara depresi dan sedih.** Sedih adalah reaksi normal pada saat seseorang kehilangan sesuatu. Lebih sulit mendiagnosa depresi.

Kadang diekspresikan sebagai gangguan somatik. Kadang bercampur dengan kecemasan.

Kemampuan bersosialisasi sering menutupi adanya depresi.

**Depresi adalah penyebab penderitaan yang reversible.**





## **Depression**

**Recommended medicines for inclusion:**

**AMITRIPTYLINE** and **FLUOXETINE**

**Recommended formulations for inclusion:**

Amitriptyline: Tablet: 10 mg; 25 mg

Fluoxetine: solid oral dosage form 20 mg (as hydrochloride)

**New recommended dosage forms for addition:**

Amitriptyline: tablet 75mg

# kecemasan



Cemas dan takut banyak dijumpai pada pasien stadium lanjut. Cemas dapat muncul sebagai respon normal terhadap keadaan yang dialami.

Mungkin gejala dari kondisi medis, efek samping obat seperti bronkodilator, steroid atau metilfenidat atau reaksi fobia dari kejadian yang tidak menyenangkan seperti kemoterapi.



## **Anxiety**

**Recommended medicines for inclusion:**

## **DIAZEPAM and LORAZEPAM**

**Recommended formulations for inclusion:**

Diazepam:

Injection: 5 mg/mL

Oral liquid: 2 mg/5 mL

Rectal solution: 2.5 mg; 5 mg; 10 mg.

Tablet: 5 mg; 10 mg.

Lorazepam:

**New recommended formulation for addition:**

Lorazepam: tablets 1mg and 2.5mg



# Respiratory Tract Secretions

## Death rattle

= a gurgling sound heard in a dying person's throat.

## **Respiratory Tract Secretions**

**New recommended medicine for addition:**

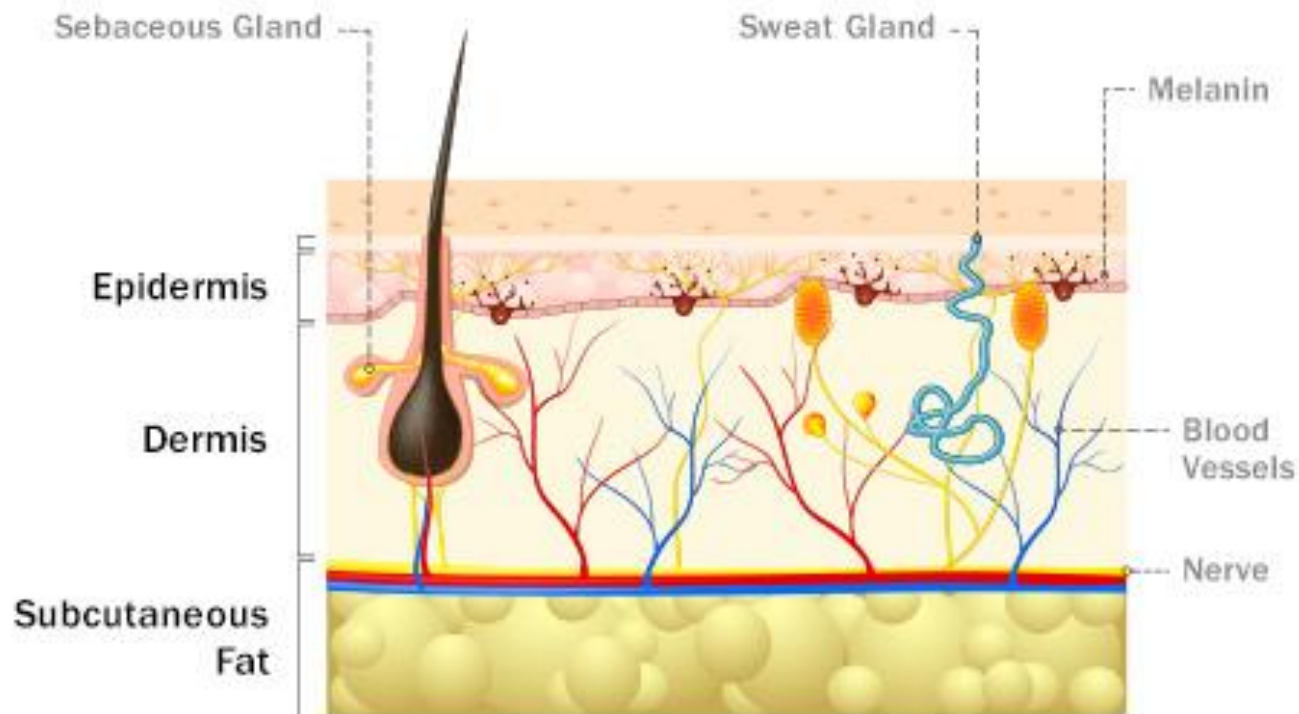
## **HYOSCINE BUTYLBROMIDE**

**New recommended formulation for addition:**

**10 mg/mL injectable**

# masalah kulit

## Skin Structure





## ULKUS DEKUBITUS

# Anticipatory Medicines

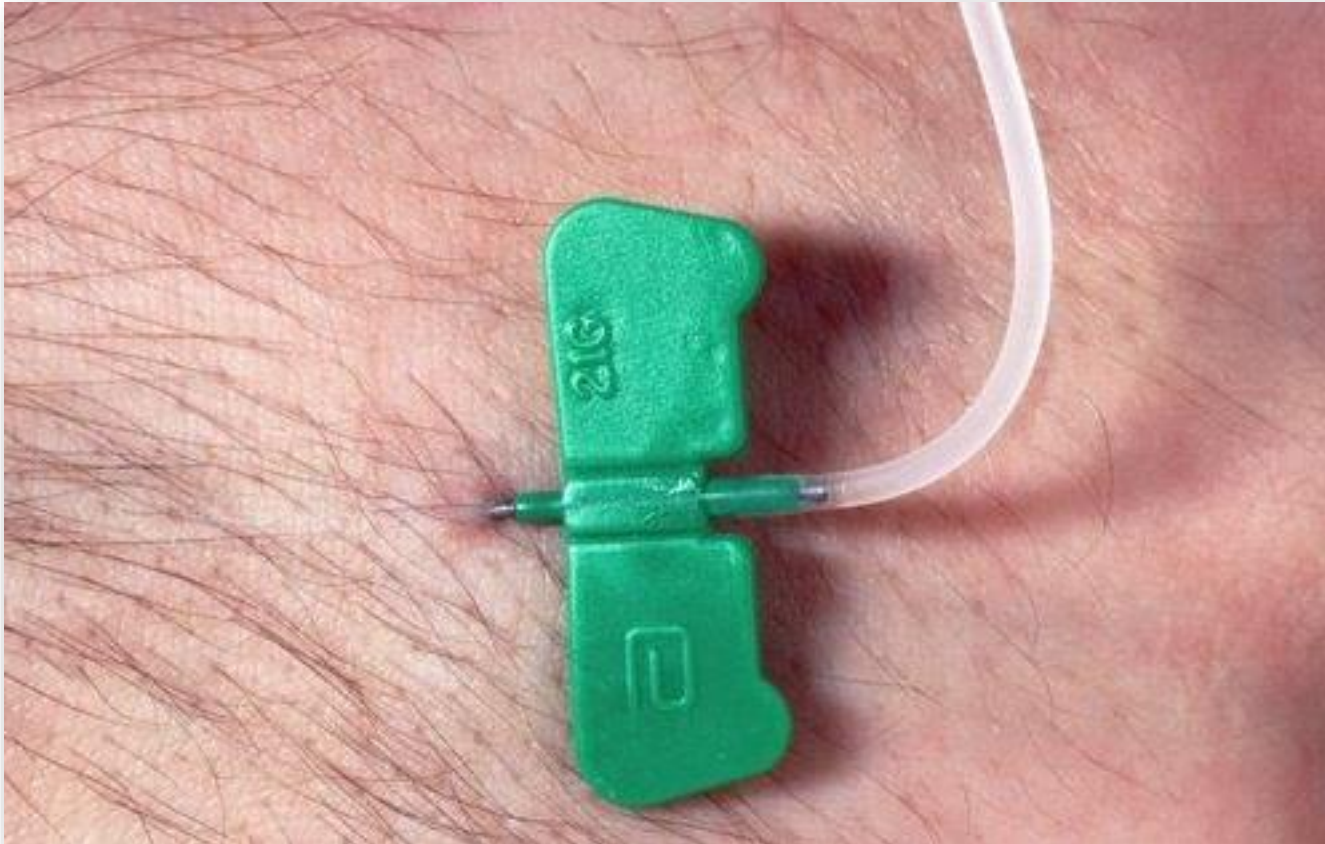
## 'Just in Case' medicines



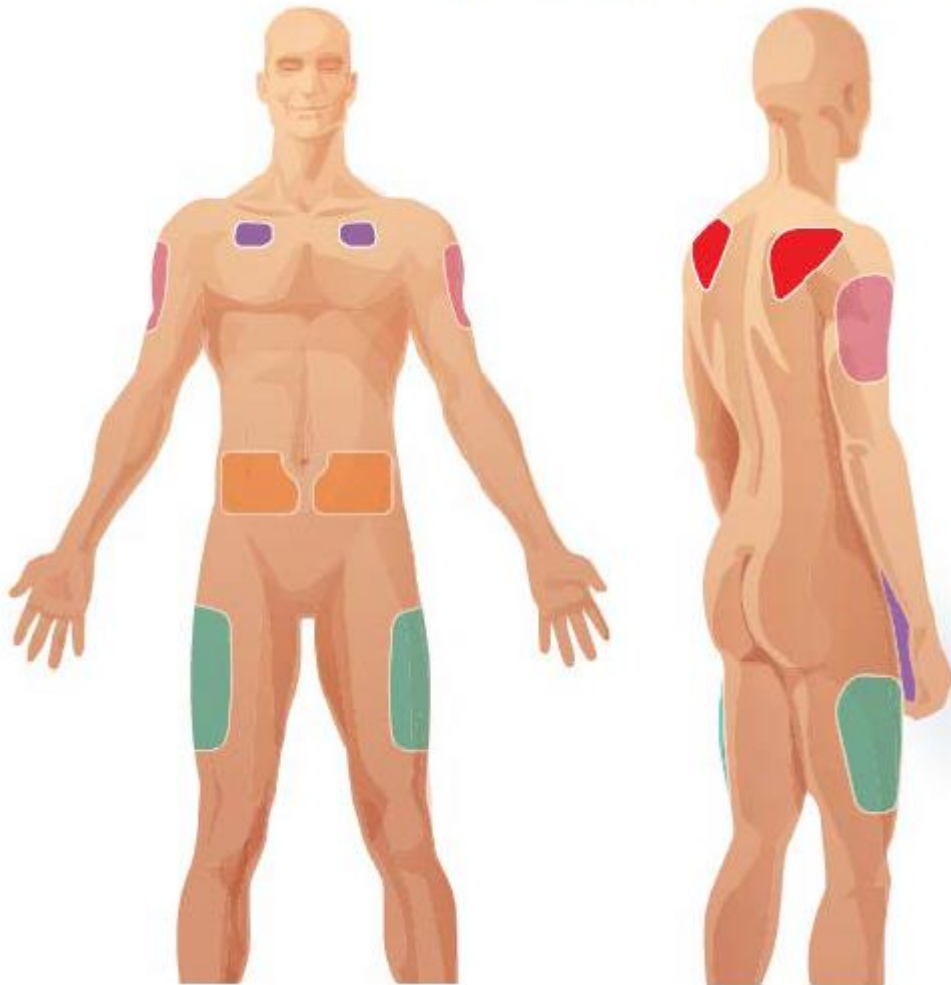
- Pain
- Shortness of breath
- Sickness/Nausea
- Secretions in the throat
- Restlessness/agitation



# Infus dan Injeksi Subkutan



## SUBCUTANEOUS INSERTION SITES



### **Upper Back (Scapula)**

Use when other sites unsuitable or client confused/restless

### **Subclavicular Area**

Avoid when client:

- has lung disease
- is active (risk of pneumothorax)

### **Upper Arms**

Avoid if possible for HDC

### **Abdomen**

Avoid in presence of tense abdominal pressure

### **Thighs**

Best location for HDC

# When Death Nears:

- Sleeping
- Loss of Interest in Food and Fluids
- Coolness
- Changes in Skin Color
- Rattling Sounds in the Lungs and Throat
- Bladder and Bowel Changes
- Disorientation and Restlessness
- Surge of Energy
- Breathing Pattern Changes

# MOTTLED SKIN

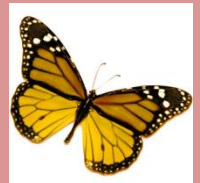


Mottled skin occurs before death and is a strong indicator that death is imminent.

# WITHHOLD & WITHDRAW

Tidak memberikan dan Menghentikan

Obat-obatan, Tindakan dan Pemeriksaan mungkin perlu dipertimbangan untuk tidak diberikan, dan yang sudah diberikan tidak diberikan lagi.



Sesuai prinsip perawatan paliatif, tujuan terapi pada pasien stadium terminal adalah untuk mencapai kondisi nyaman dan meninggal secara bermartabat.

**Sehingga terapi yang diberikan bertujuan untuk memperpanjang proses kematian harus dihentikan dan terapi yang tidak sesuai dengan tujuan di atas tidak mungkin diberikan.**



## 2. Reviewing Regular Medication.

The patient may have an altered level of consciousness or significantly reduced oral intake and therefore struggle to swallow medication. Review current medication and discontinue any medication that is no longer of benefit to the patient. For example:

Anti-Hypertensives	Corticosteroids	Hypoglycaemics*
Antibiotics**	Diuretics**	Iron / Vitamin preparations
Anti-arrhythmics	Haematinics	Statins
Anti-coagulants	Hormone therapy	Steroids (long term)***



Catatan Pengkajian, Rencana

Instruksi/Order

Profesi  
Nama,  
Tgl.Verifikasi  
DPJP/PPJA  
Utama  
(Nama,  
TTD, Tgl,  
Jam)

## deprescribing

Psikow. Keluarganya mau ke Uluw.  
 Under all Keyes  
 home. Inj 0.5% / Nacc 9% → 20 ths per.

Spinal: lila

Uluw: - Ondansetron

- Lansoprazole

- Levofloxacin

- VA B1 B2 B12

- Domperidone

- Subnifast

- Donepezil

- N Acetil cystein

- Prilidex

- Bisolvon

Diazepam 2x → stop.

STOP.

- Family conference. Senin. 11/11/2019  
 - Kumpul keluarga  
 - Usaha Van der Horst  
 - 8 d 11/11



# Palliative sedation

In medicine, specifically in end-of-life care, palliative sedation (also known as terminal sedation, continuous deep sedation, **or sedation for intractable distress in the dying/of a dying patient**) is the palliative practice of relieving distress in a terminally ill person in the last hours or days of a dying patient's life,

From Wikipedia

# Palliative sedation

usually by means of a continuous intravenous or subcutaneous infusion **of a sedative drug**, or by means of a specialized catheter designed to provide comfortable and discreet administration of ongoing medications via the rectal route.

From Wikipedia

# DEATH

Here are indications  
that death has occurred:

- **No breathing for a prolonged period of time**
- **No heartbeat**
- **Eyes are fixed and slightly open, with enlarged pupils**
- **Jaw relaxed, with the mouth slightly open**

# GOOD DEATH

KHUSNUL KHATIMAH

## Principles of a good death

1. · To know when death is coming, and to understand what can be expected
2. · To be able to retain control of what happens
3. · To be afforded dignity and privacy
4. · To have control over pain relief and other symptom control
5. · To have choice and control over where death occurs (at home or elsewhere)
6. · To have access to information and expertise of whatever kind is necessary
7. · To have access to any spiritual or emotional support required
8. · To have access to hospice care in any location, not only in hospital
9. · To have control over who is present and who shares the end
10. · To be able to issue advance directives which ensure wishes are respected
11. · To have time to say goodbye, and control over other aspects of timing
12. · To be able to leave when it is time to go, and not to have life prolonged pointlessly

# GOOD DEATH

KHUSNUL KHATIMAH

## Principles of a good death

- The ability to anticipate death and manage expectations
- Access to any necessary information resources and support, both spiritual and emotional
- Control over the situation, including pain relief, privacy, location of death and individuals present, combined with confidence that any predetermined instructions will be followed
- Maintenance of a sense of dignity
- Avoidance of needless prolonging of life, balanced with adequate time to say goodbye

<https://www1.racgp.org.au/ajgp/2018/november/home-based-palliative-care>

# What is a good death?

A good death is the best death that can be achieved in the context of the individual's clinical diagnosis and symptoms, as well as the specific social, cultural and spiritual circumstances, taking into consideration patient and carer wishes and professional expertise.

**A supportive culture that fosters excellence, confidence, innovation and education in all staff with the aim of improving outcomes**



**Timely assessment and provision of bereavement services**



**Care which is competent, confident, compassionate and personalised, in line with recognised best practice standards**



**Joined up, co-ordinated services and pathways which are easy to access and navigate**



**Access to spiritual and psychological support**



**Tailored pain management**



London Strategic Clinical Networks | 105 Victoria Street, London, SW1E 6QT | [england.london-scns@nhs.net](mailto:england.london-scns@nhs.net) | [london.scn.nhs.uk](http://london.scn.nhs.uk)

<http://www.london.scn.nhs.uk/wp-content/uploads/2014/11/eolc-good-death-definition-052015.pdf>

An article in the Journal of the American Medical Association found that there is no one definition of a good death; quality end-of-life care is a dynamic process that is negotiated and renegotiated among patients, families, and health care professionals.

<http://www.bbc.co.uk/ethics/euthanasia/overview/gooddeath.shtml>



# FUNERAL



*BIMTEK PELAYANAN PERAWATAN PALIATIF DAN AKHIR KEHIDUPAN  
RSUD TUGUREJO  
KAMIS, 13 FEBRUARI 2020*



# COMMUNICATION IS



Providing good psychosocial care  
comes down to good  
communication skills, both  
**verbal and non-verbal.**

# PALLIATIVE CARE







## **TAMAN PALIATIF RSUP DR KARIADI SEMARANG, 2019**

*BIMTEK PELAYANAN PERAWATAN PALIATIF DAN AKHIR KEHIDUPAN  
RSUD TUGUREJO  
KAMIS, 13 FEBRUARI 2020*





Nama:

**Prof. Raden Sunaryadi Tejawinata,**  
dr. SpTHT(K-Onk), FICS, FAAO, PGD,  
Pall.Med.(ECU)

Lahir:

**Cirebon, 23 Agustus 1934**



Prof. Sunaryadi

**BAPAK PALIATIF INDONESIA**

REVISI KELOMPOK PELAYANAN PERAWATAN PALIATIF DAN AKHIR KEHIDUPAN  
RSUD TUGUREJO  
KAMIS, 13 FEBRUARI 2020

# **DEKLARASI PERDOPIN**

## **(Perhimpunan Dokter Paliatif Indonesia)**



**Surabaya, 22 Februari 2014**

*BIMTEK PELAYANAN PERAWATAN PALIATIF DAN AKHIR KEHIDUPAN*

*RSUD TUGUREJO*

*KAMIS, 13 FEBRUARI 2020*



## APHC 2019 - 13th Asia Pacific Hospice Conference

Aug 01 - 04, 2019, Surabaya

BIMTEK PELAYANAN PERAWATAN PALIATIF DAN AKHIR KEHIDUPAN  
RSUD TUGUREJO  
KAMIS, 13 FEBRUARI 2020

## TAKE HOME MESSAGES

### **Palliative care allows for medical therapies, but focuses on:**

- Improving quality of life
- Relieving symptoms (for example pain) and stress
- Reaching the best possible function (for example, daily activities, physical activity, and self-care)
- Helping with decision-making about end-of-life care
- Providing emotional support to patients and their families

<https://www.stanfordchildrens.org/en/topic/default?id=palliative-care-90-P03053>



## TAKE HOME MESSAGES

1. **identify:** earlier identification and recognition of patients in final year/s:
  - to ensure equity of access, leading to better proactive planning of care for all
2. **assess:** use advance care planning discussions:
  - to clarify people's needs, wishes, and expectations
3. **plan:** planning for patients to live well and die well where they choose:
  - through better coordinated care, reducing hospitalisation.

<https://www.guidelinesinpractice.co.uk/cancer/going-for-gold-helps-to-improve-access-to-better-end-of-life-care/352561.article>

e



## **TAKE HOME MESSAGES**

- 1. Each person is seen as an individual**
- 2. Each person gets fair access to care**
- 3. Maximising comfort and wellbeing**
- 4. Care is coordinated**
- 5. All staff are prepared to care**
- 6. Each community is prepared to help.**

<https://www.england.nhs.uk/wp-content/uploads/2016/01/transforming-end-of-life-care-acute-hospitals.pdf>

# 7c

## The seven Cs of primary palliative care

- Communication
- Coordination
- Control of symptoms
- Continuity of care
- Continued learning
- Carer support
- Care of the dying pathway

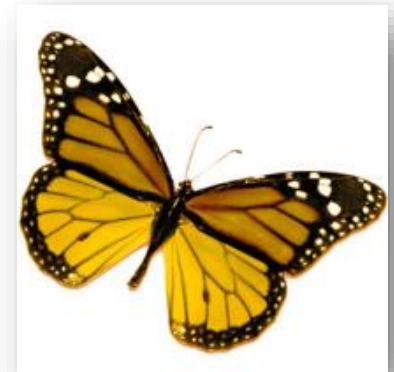


<https://www.mja.com.au/journal/2010/193/2/palliative-care-beyond-cancer-australia>

## SUGGESTED READING

# **RESOURCES** TO SUPPORT YOUR CONTINUED LEARNING ABOUT **PALLIATIVE CARE AND END OF LIFE CARE**

- ❑ <https://acclaimhealth.ca/programs/palliative-care-consultation/palliative-care-resources>
- ❑ <https://www.palliativecareguidelines.scot.nhs.uk/guidelines.aspx>
- ❑ <https://www.ontariopalliativecarenetwork.ca/en/node/31896>
- ❑ <http://www.mhpcn.net/palliative-care-toolbox>
- ❑ <https://library.nshealth.ca/PalliativeCare>
- ❑ <https://palliativecareindonesia.blogspot.com>



Rumah sakit menetapkan proses untuk mengelola  
**ASUHAN PASIEN DALAM TAHAP TERMINAL.**

*Proses ini meliputi*

- a) intervensi pelayanan pasien untuk mengatasi nyeri;
- b) memberikan pengobatan sesuai dengan gejala dan mempertimbangkan keinginan pasien dan keluarga;
- c) menyampaikan secara hati-hati soal sensitif seperti autopsi atau donasi organ;
- d) menghormati nilai, agama, serta budaya pasien dan keluarga;
- e) **mengajak pasien dan keluarga dalam semua aspek asuhan;**
- f) memperhatikan keprihatinan psikologis, emosional, spiritual, serta budaya pasien dan keluarga.

[http://www.pdpersi.co.id/kanalpersi/manajemen\\_mutu/data/snars\\_edisi1.pdf](http://www.pdpersi.co.id/kanalpersi/manajemen_mutu/data/snars_edisi1.pdf)

*BIMTEK PELAYANAN PERAWATAN PALIATIF DAN AKHIR KEHIDUPAN  
RSUD TUGUREJO, SEMARANG. (13 FEBRUARI 2020)*







# THANK YOU

<https://palliativecareindonesia.blogspot.com/2019/12/dari-sebuah-rintisan-menuju-paripurna.html>